



Kelly Howard

Before the  
Education Committee

Regarding:

R.S.B. 1054 An Act Concerning Students With Dyslexia

March 11, 2015

Good Afternoon Chairman, Senator Slossberg, Representative Fleischmann and other members of the Education Committee. My name is Kelly Howard, mother of Zoey and Katie Howard. Thank you for the opportunity to address you today on the proposed bill listed above.

My daughter Zoey Howard is a 7 year old Fraternal Twin. She is currently in Second grade attending Bakerville Consolidated Elementary School in New Hartford, Connecticut. She was diagnosed in first grade (January 2014) with a Language Based Learning Disability/Dyslexia and Expressive Language Disorder.

The first signs of learning based difficulties arose in preschool at Zoey's year-end assessment. She had great difficulty retaining the alphabet and names of shapes. The Director of the program was very concerned about the results. At the time I became angry with them, thinking they had not spent enough time teaching my daughter. They wanted us to hold Zoey back from going into Kindergarten. I was furious! Why isn't Katie having a problem learning this? It had to be there fault and I was angry with them after all we paid a lot of money for this school. I would later find out these were the first early identification red flags of Dyslexia that someone with proper training would have picked up on. My husband and I would not know about Dyslexia until approximately 1 year later. I was embarrassed about how angry I got at them looking back on the situation. We had no idea.

The following year Zoey and her Sister Katie began a half day Kindergarten program at Bakerville Consolidated Elementary School. Zoey and Katie were in the same class. The school used the "Dolch" method to memorize high frequency words. Part of their program was a requirement to memorize 25 "popcorn" words. Pop because they frequently pop up. Katie learned the words with relative ease. Zoey struggled and struggled. Neither my husband nor I knew what was wrong. We tried everything. Zoey could remember some of the words Monday and then forget them by Wednesday. At first I thought she was just being lazy and I would get upset. I would tell her let's just keep practicing. I had no idea what she was going through. It was such a difficult task for her. I even told her when she could get all the words memorized I would take her to NY City to buy an American Girl Doll. I was desperate to get her to learn these words!

It was in November 2013 the time of the Teacher Parent conference that we learned something was wrong. I remember going into that conference so happy thinking I was going to be told how smart my girls were. Instead the teacher looked at Tim and I and asked if we wanted the good news or the bad news? Foolishly, we took the good news first. Katie was learning well and at the high end of her class. As for Zoey, her teacher said, "I do not know what is going on."

It was like an out of body experience for me as Zoey's teacher walked us through the work she had been doing with my daughter, explaining to us what she was experiencing. Here we had one child doing so well while the other struggled. The teacher told us a story about a circle time experience in which she call on the kids to answer various questions. Being selected is a real honor and the kids clamor to be picked. In this instance, the teacher picked Zoey but Zoey could not answer the question. The other kids were all yelling "I know it; I know it; pick me."

Katie got so upset she yelled at her sister, "Zoey, you know this. I know you know this. Just answer the question."

I could feel the pain and embarrassment my little girl must have felt. It went on and on. The last story the teacher told us was about an independent timed test she had given the class. They were to write down a few of the so called 'popcorn' words in a simple sentence and draw a picture. She told me Zoey froze, that she was confused and didn't know what to do. She looked around to her friends and tried to see what was on their papers. The teacher said she could see Zoey struggling but it was meant to be an independent assignment. She knew it was uncomfortable for Zoey but she could not do anything. All I could think was how awful my poor little girl must have felt. I wished I could have been there with her. I kept picturing her young little face looking for help. The teacher asked us if we noticed anything before. My mind raced back to the conversation I had with the Director of her preschool. I immediately started to feel panic.



**This teacher was so on the ball.** When she explained to us what she was seeing she was so clear and to the point. She was very careful and never implied anything, but she clearly made it apparent we needed to pay attention. She told us she spoke to the Special Education Teacher about Zoey and they implemented extra help. Zoey would be working with a Paraprofessional.

(I feel it is important to note here, because of this teacher's early identification and very detailed description of Zoey's difficulties; after months of research I came to believe that Zoey had Dyslexia. Looking back the signs were so clear to me.)

After the conference, I went and sat in my car and cried. I felt like someone had punched me in the stomach. I was completely devastated. I began to question myself and everything I had done as a parent up until this point. After all I must have done something wrong. Maybe it was because I worked and I did not stay home with the girls? All I knew was I had to do something fast, I was not going to let my child fail. Poor Katie; that night when

we got home from the conference we could not even celebrate her achievement the way we should have. I regret that now. I was so worried about Zoey.

Within a few days I reached out to a friend of mine who had a business called Little Hands Big Ideas. She teaches children sign language and intensive reading. The fees were \$100 an hour. It was a lot, but we were desperate. I hired her to work with Zoey in the morning before Kindergarten then she would drop her off at school for me. Zoey worked with Colleen through the end of the school year in mid-June.

At school Zoey was getting extra with a paraprofessional and her Teacher. At this point, Zoey told me **she did not like school anymore**. She did not want to go back. She just wanted to go to camp. It must have been hard for her. My husband also told me a sad story. He took the morning off so he dropped Zoey off at Colleen's for her tutoring session. He said Zoey was so excited in the morning; she put on her usual big puffy fairy party dress for school and a fancy headband with a big bow. Tim said when he pulled up to Colleen's house; he looked in the rear view mirror at Zoey in the backseat. Zoey took a deep breath (out of frustration) and lowered her head. Tim said it was the saddest thing he ever saw. Zoey slowly took off her headband, paused for a moment like that and then reached out her little hand out to him and gave him the headband. She said she didn't feel like wearing it anymore. Then with a lowered head and a sad face she got out of the car and went into Colleen's house. Tim said it was not Colleen; Zoey liked her. It was that she had such difficulty learning to spell it was uncomfortable for her.

Despite her difficulty learning to read, Zoey loved books. In fact my husband and I noticed something weird. In the morning we would find all these books in a pile on the floor in front of the book case in the girls' bedroom. We were not sure which one of them was doing it. It was one night after everyone went to bed I heard something so we went down to the girls room. There was Zoey with her little head lamp on going through the book shelf. One by one she would pull a book out, open it try to read it then throw it in the pile on the floor and pick another one. After a while of watching her we asked her what she was doing? She said she wanted to see if she could read. We would often find books in her bed in the morning.

I started to do a crazy amount of research trying to figure out what was going on with Zoey. I found the National Center for Learning Disabilities, NCLD. From there I made the connection to Dyslexia. They had a lot of information and checklists. I could see similarities in the symptoms the teacher explained to us and what I was reading. In the mean time we had another meeting with Zoey's teacher.

That was the first time I brought up Dyslexia and it was like I said a four letter word. She clearly got uncomfortable talking about it. So I did not press it. She recommended we have Zoey tested for a learning disability. She said this will identify her weaknesses and the best way to teach her. She said that we would have to make a request for the evaluation. All the time she spoke to us it was as though she was being very guarded or at least that was my impression. She could not just come out and tell us what she thought. I remember thinking to myself, "Please just tell me!! I promise I won't get mad!" Instead I just followed her lead; it was all I could do at the time.

I formally requested an evaluation for Zoey. It was performed by Meagan Brown the School Psychologist, Don Tobias Speech/Lang, Mrs. Baillargeon her Special Education Teacher. Before we started the testing I told them I had a concern about Dyslexia. Again they all gave me the same reaction. I wondered what was I missing here?

It was very weird. I told them my younger brother had it, though I did not know much about it. They noted my concern and scheduled the testing. When the results came back we had another meeting.

At that meeting, they discussed the results of their respective evaluations and made recommendations. Don Tobias thought Zoey was a bright, articulate, curious child. Initially he thought she did not need extra help. Katie Baillargeon looked at me and shook her head no. She knew that Zoey would need help and she gave examples. Megan Brown agreed with her assessment. They had some more discussion then they were all on the same page. They were setting up an IEP for her. I had never heard this term before. In fact they were using a lot of terms I had never heard before. At this point in time I felt like I did not understand what they were talking about. The conversation was whizzing around my head. It was as though I had to attend a board meeting at work and I never prepared for it. I was not comfortable with this not understanding what was going on. I had to blindly trust them. From that point forward I vowed to myself I was going to make it my responsibility to understand everything for my daughter's sake.

I soon realized that Zoey would have to be labeled as Special Education to get the help she needed. I knew it was the right thing to do, but I got choked up as I fought back tears. It hit me my child was going to be in special education. Her teacher reached out to me and said, "it is okay; you are doing the right thing." They told me I had to sign a form and that they were going to create an IEP for Zoey. Again this was unfamiliar to me. I signed it. There was a list of 2 PPT Recommendations. I will never forget this. The first sentence read Zoey qualifies for special education services as a student with a **Learning Disability**. And then our journey began.

\*\*\*The people performing Zoey's evaluation were not specifically trained in 2013 (when they did her evaluation) to screen for Dyslexia, to identify Dyslexia. Show me where you were trained on Dyslexia? How many hours of Dyslexia training did you have? How could they identify Zoey's Dyslexia? Someone needs to validate this. If I listened to the School Zoey would have gone undiagnosed for Dyslexia.\*\*\*

I spoke with my pediatrician, Doctor Robert Toscano, who has been a great help to us throughout this process. He told us to keep very detailed records and ask the school to give us weekly evaluations. He said this was very important to tell if the learning gap was widening or closing. I also spoke to him about getting Zoey tested for Dyslexia. He would look into it for us.

At the end of the school year, Zoey's teacher helped me find a tutor to work with Zoey over the summer. I did not know about Extended School Year Services, and no one mentioned it to me either. As a favor to Zoey's teacher a second grade teacher offered to work with us. She came to our house every day to work with Zoey over the summer so she could maintain the gains she had achieved in Kindergarten. Some days I was running late, so I would over hear them. It was then I could see the full impact of the difficulties Zoey was going through. This teacher was good, she tried everything, but it was like someone was taking Zoey's hands and sticking them in fire. The teacher told us she felt so bad. She tried every trick she knew. She apologized to us saying, I was hoping to have some type of breakthrough." She did not even cash the last weeks check gave her because she felt so bad.

At that point, I knew this was more serious. The school evaluation did not tell us what was wrong. All I came away with was that she needed extra help learning to read. My gut feeling was something was seriously wrong, and we needed to get some answers. I called my pediatrician and asked him to recommend a good Doctor to do

a Neuropsychological Evaluation. (I had just recently learned this term from Dr. Toscano) He told me to call Dr. Isenberg at Connecticut Pediatric Neuropsychology Associates. This was in July; the first appointment I could get with Dr. Isenberg was January 8, 2014.

We were at the end of Kindergarten; the next step was first grade. Zoey was so scared of school at this point, she was clinging to Katie. I felt this would hold Katie back. She also started to get angry with Katie because she was able to learn. I knew in my heart the girls would have to be separated. It was difficult but we did it. Zoey became very upset about it. She came home from school and said, "Mommy did you tell them to split us up? Now I am afraid that Katie and I will never be together again." I looked at her sad little face, she was so upset, and I could not tell her the truth. She would never understand. I said, "No, Zoey; the school separated you two." It would have hurt her more if I told her the truth. At 5 years old, she would not have understood.



In September when school started I called Katie Baillargeon and told her I wanted to have Zoey tested for Dyslexia. At first she said I don't think you can test for that before second grade. I knew now from my extensive research over the summer that was not true. I told her you can test now; I have the research I can send you. She took a moment to think about our discussion and she said, isn't that what we just did? She was referring to the evaluation the school had just performed. I kept pushing the point of Dyslexia testing. I said I have a lot of resources I can e-mail you the information. She told me not to e-mail it to her because it would be discoverable. I do not even think she realized what she said. I work in the Law Department for the Hartford doing compliance work-I was shocked! I did not say anything. I just kept thinking, "I can't believe she said that to me."

We had a meeting with our PPT Team in September 2013; I told them I scheduled the Neuropsychological Evaluation. The Director of Special Education told me flat out they would not pay for it. Again I did not know if I did not agree with the schools evaluation that I could request that she be reevaluated. That is my fault for not completely understanding a Parent's Guide to Special Education. For the record no one on the PPT team informed me of my rights either. They did agree to provide me with weekly evaluations so I would be able to provide the doctor with Zoey's school history. They were very good about this. Everyone was always very nice to us and to Zoey. In early October Zoey's first grade teacher performed a Fountas and Pinnell reading assessment to see where here students were, Zoey was an A, Kindergarten level. This is after being tutored one on one everyday over the summer. This was another big red flag that we were dealing with something more involved.



In January 2014 we had Zoey's Independent Evaluation. Our insurance did not cover this; they told us the school should be providing it, it is an Educational Cost. We knew that was not going to happen, we had to pay the \$2,500 at the time of the visit. They were very clear about this. We just had the evaluation and received the report. We also paid for an extra consultation with our PPT Team to discuss the results of the report. Dr. Isenberg made a lot of suggestions. When he met with Tim and I to go over the results, he told us that Zoey was going to need a lot of one

on one intervention. He said because she was identified so early, we could have a positive outcome.

We hired a tutor trained in both the Orton-Gillingham and Lindamood Bell methodology working with Zoey three days a week after school (\$75 dollars an hour.).

Upon getting the detailed report from Dr. Isenberg Tim and I hired an advocate from SpEdCT. It was becoming very overwhelming for me. I was trying to stay on top of the latest Dyslexia research as well as continue to inform myself on Zoey's rights for FAPE. When we met with the PPT Team after going through Dr. Isenberg's results I requested a full record review and reading evaluation from Literacy How. Dr. Isenberg told us what was wrong, now we need a road map to get Zoey on track. The town agreed to pay for this. I am very thankful. This evaluation is the single most important thing we have ever done for Zoey. Literacy How came to the school and observed the teachers working with Zoey. They also performed specific testing and gave us 19 specific recommendations. The two most important... "Zoey requires continued use of a research---based, multi-sensory, systematic and explicit reading program to strengthen her decoding, word recognition, encoding and reading fluency skills. This program is essential to help close the gaps in reading so that Zoey can reach her full potential. Whatever multisensory language (MSL) program is chosen, it must be delivered intensively, meaning 5 days a week, for a minimum of **90--120** minutes each day. Examples include, but are not limited to, Wilson Reading System, Orton---Gillingham or Nanci Bell's Seeing Stars Program. 2. If a specific program is chosen for Zoey to participate in, the individual(s) who work with Zoey (i.e., special education teacher and speech and language pathologist) **must have authentic training in that program** so that the program is carried out with fidelity. If they are newly trained in a program, they will require a mentor/consultant to assist with initial program implementation. This year we requested **Extended Year Service**.



Zoey was 6 years old. The school offered to bus Zoey up to the Regional School for Summer School. That is a 50 minute ride each way. Zoey would be on that bus and at school with all older children. She would be terrified. There was no way I would do that to my child. I could not even believe they thought that was a feasible option. I said No!

Next they offered 3 days a week for 45 minutes at the local library. (Nowhere near the 5 days a week, not even 90 minute sessions) I asked to see the credentials for the person that would be delivering Zoey's program. We requested someone authentically trained.

We also wanted to see their certification. It turned out that no one at Bakerville School or Regional had that training. It was all learned on the job by someone else who had some training. So if they learned from someone doing it incorrectly they would perpetuate that same behavior. **It was impossible to believe.**

We requested they send her to Lindamood Bell or KilDonan both have a great history for working with Dyslexic children. They denied our request immediately, due to expense. Keep in mind we were at the end of first grade and Zoey was reading at a Pre-Kindergarten level. Tim and I were worried. We rescheduled another meeting.

The school found a woman at Antolini School that had training by Scottish Rite in Waterbury. It said it was an Orton Gillingham (OG) program. I contacted the Academy of Orton Gillingham Practitioners in Amenia NY. They told me this was not an OG program and they did not know the woman that signed off on the certificate. I e-mailed them a copy of it. They provided me a list of authentically trained OG instructors in CT. It turned out the program is **based on** Orton Gillingham methodology. That is different than Orton Gillingham certified. There is a lot of rigor and training involved in obtaining an OG certification. It is not a one week course.



The school offered 45 minutes a day at the Town Hall for a total of 17 days over the summer. They denied our request for transportation. If the school district provides transportation to Zoey during the school year and she has an IEP, under IDEA or CT guidelines isn't she entitled to transportation? We had to take it or leave it. We took it, it was better than nothing. I told them I was going to retain an attorney for Zoey. At this point we were beyond frustrated. Just a note, right after that our Director of Special Education resigned and our Superintendent left our district.

For the summer program Tim and I hired a tutor that was on the list provided to us from the Academy of Orton Gillingham Practitioners in Amenia NY. We ended up paying \$450 a week. The tutor was \$75 an hour 5 days a week (33 days in total) and we had to pay for transportation to take Zoey from the town hall to camp. Tim and I both work full time.

When school started and we had our PPT with the new Director of Special Education, we asked to be reimbursed for the summer school cost we incurred. She said flat out **no**! We asked if the school would hire a certified OG tutor to work with Zoey during 2<sup>nd</sup> grade, she also denied that request. Then we asked if the school would pay for qtrly independent progress monitoring delivered by Literacy How, they said **No**! They would have someone in district perform the monitoring. I asked what her training was in Dyslexia; I was never provided the information. I feel like they always say **no** to my requests. However, Paula did say yes to my request to have Zoey's IEP form updated, that gesture made me happy. Zoey has the new 2015 IEP form with an X next to SLD –Dyslexia.



Tim and I will have Literacy How do Independent Progress monitoring this month. We want an objective unbiased assessment. We will continue to provide an OG tutor for Zoey. We continue to keep up on the latest Dyslexia research. Zoey participated in the BILD study up at MIT in October 2014 at the Gabrieli Lab. They did a fMRI brain scan (we were given a free copy) and other assessments. Results will be published in a science journal. 3 weeks ago we took her up to TUFTS University, where she participated in a study by Dr. Melissa Orkin the Director of the Center for Reading and Language Research. We will get free assessments and reports from both studies.

At the end of the day the experts basically all say the same thing. These kids just need early identification and a good multisensory language (MSL) program delivered intensively. The person delivering it **must have authentic training in that program** so that the program is carried out with fidelity. If Teachers are newly trained in a program, they will require a mentor/consultant to assist with initial program implementation.



Require that our teachers have Dyslexia training through professional development and higher education. If it is not a requirement it will not happen. Ask yourself, has it been happening on its own so far?

Before I close I would like to emphasize how much out of pocket money we have spent to get the right help for Zoey and we are still not there. Insurance has not covered any of this. Fortunately we were able to do this on our own with great sacrifice. Many families may not have the resources to have their child tested; due to expense may not be able to

afford tutoring. Consequently, the child will struggle, possibly fail and not receive the proper training needed to succeed. No child deserves this.

We have valuable resources right here in Connecticut at the Yale Center for Dyslexia & Creativity, Haskins Lab, Literacy How to name a few. The research has already been done. Let's give the schools and teachers the tools they need to define and understand Dyslexia, provide approved testing and evaluations, and give educators the right tools and training to work with and to provide special curriculum designed for Dyslexic students. The State Legislation has the power to define the Dyslexia, bring it front and center in the educational system and provide Dyslexic children with the education they so richly deserve.

I ask that you support S.B. 1054, An Act Concerning Students with Dyslexia, but I am also requesting additional support in the form of early identification requirements, appropriate researched based intervention for the children of CT and require that our teachers have Dyslexia training through professional development and higher education. I will end here and thank you for your time. Please help these children to prosper, they do not want to fail and they have so much potential!

As a resident in the State of Connecticut, I request your support of the Dyslexia legislation.

Respectfully,

Kelly Howard

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